



Ethnicity and health beliefs with respect to cancer: a critical review of methodology

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Summary This paper considers methodological issues raised by investigations into the relationship between health beliefs with respect to cancer and ethnicity. Because what people will proffer in response to a question about their health beliefs and ethnicity depends amongst other things, on the time and place of asking, and the identity, purpose and methodological approach of the person posing the question, we have focused exclusively on British material; also the practical issues discussed are largely relevant to Britain only.

Qualitative or quantitative methodology?

It would be a mistake to understand the relationship between qualitative and quantitative research as a competition. The two approaches should be regarded as complementary rather than competitive.¹ In this paper we argue that qualitative methods are particularly effective in investigations of health beliefs. They can discover why for example, predictive models of health behaviour such as the Health Belief Model, discussed below, fail. The data they obtain can serve as powerful reminders of the complexity of human beliefs and behaviour.

Anthropologists were the first to investigate health beliefs using the ethnographic method in exotic locations. Anthropologists advocate a qualitative methodology,^{2,3} using participant observation as their instrument of research; the investigator lives with the group or community being studied, and perhaps takes a direct part in their activities. The classic study here is Evans-Pritchard's *Witchcraft, Oracles and Magic among the Azande* in which he describes how the Zande explain misfortunes, including illness, in terms of supernatural forces.⁴ Evans-Pritchard drew attention to the fact that beliefs about health occupy the same realm as other everyday concerns such as food, children, and other relationships, a point which we will return to. More recently, some sociologists have exploited the anthropological method in their own country, believing that its strength lies in allowing people's own story to emerge. The method has paid dividends. Cornwell⁵ spent a considerable amount of time with a group of closely related working-class people who lived in Bethnal Green, London. Although she did not live with them, she gained their confidence through familiarity. Because they felt comfortable with her, she became party to ideas that they may have withheld from other researchers. She discovered that lay people articulate two sorts of health beliefs which she called their 'public' and 'private' accounts. In their public accounts of health, illness and health services, people draw attention to aspects of experience, ideas and values that they believe are acceptable to doctors and 'fit' with a medical point of view. Public accounts exclude those parts of people's experience and opinions that might be considered unacceptable and not respectable. The experiences and opinions expressed in people's private accounts are only accessible through a methodology which allows respondents to voice their thoughts.

A major weakness of participant observation is that it is time consuming; it is difficult to cover anything other than small numbers of subjects. The method has been criticised as being subjective and 'unscientific'⁵ although the investigators who champion it have never claimed otherwise.^{6,7} Their project is to understand human action: the meanings lay people themselves impute on illness, health and disease are the focus of investigation. People are considered to be critical, active and discriminating; their beliefs are afforded the same respect as those of the medical profession. Indeed, medical knowledge is

considered a belief system in itself,⁸ albeit one which during the twentieth century, has colonised lay people's experiences of illness and health.⁹ Stacey makes this point when she advocates replacing lay health beliefs with the term 'people knowledge' because it emphasises the major part played by non-medical professionals in the production of health and management of illness: we are all concerned with health and illness, in our homes, work, in the school, and in our everyday interactions.¹⁰ Stacey's terminology may allow investigators to sidestep the unresolved methodological issue of whether or not to elicit concepts of health in conjunction with concepts of illness, or whether the two should be sought in isolation.¹¹

An alternative method of collecting qualitative data on health beliefs is the in-depth interview, or 'conversation', which is recorded and systematically analysed using the technique of content analysis. For example, using this approach in a study of middle-aged, working-class Scottish women, Blaxter found that although their ideas about the causes of disease were 'incorrect' according to scientific medicine, they had their own internal rationality.¹² Furthermore the women's health beliefs took into account their social situation; for example, although women acknowledged neglecting their own health, they claimed that poverty, their life circumstances and responsibilities made self-care impossible. Other studies have extended Blaxter's observation that social circumstances shape health beliefs and behaviour. Charles and Walters for example found that so-called unhealthy lifestyles enable working-class women to cope; health is often of secondary importance to women confronting poverty, poor housing and unemployment.^{13,14}

Qualitative methodologies envelop the 'focus group', which was developed as a tool by market researchers. More recently it has been deployed by academic researchers to investigate amongst other things, health beliefs.^{15,16} Focus groups are group discussions; the group is 'focused' in the sense that it involves some kind of collective activity or task, such as viewing a film, evaluating a pamphlet, or discussing health beliefs.¹⁷ They have been found to be particularly useful for exploring people's knowledge and experience of specific issues. Kitzinger used this method to explore the effect of messages about AIDS in the media. In her experience, the advantage of a focus group is its capacity to exploit group dynamics.¹⁸ By encouraging participants to engage with one another, the investigator can gain insight into group/social processes; the dynamic can also help people to talk about embarrassing subjects.

Focus group studies can consist of anything from a few to over fifty groups. Each group consists of from six to ten participants. A quantitative approach to collecting data on lay health beliefs may also allow the interrogation of an even larger sample. It is taken by investigators trying to explain patterns of health behaviour.¹⁹⁻²² Unlike studies which are concerned with knowledge and meaning, and with placing health beliefs in a

broader context, these pragmatic investigations seek to develop predictive models in which health beliefs are one of several variables. A good example is a study into the complex psychosocial factors influencing attendance, non-attendance and re-attendance at a breast screening centre in an inner city area.²³ In the conclusion the researchers compare their data to the Health Belief Model^{24,25} which like the Health Locus of Control,²⁶ seeks to predict behaviour with respect to health. Both models draw on a calculus of lay health beliefs conceptualised by health professionals. In effect, they are blind to the well known gulf between lay and professional concepts. Inevitably they place unjustified emphasis on people's rationality having a scientific basis.^{11,27} Both ignore impediments to health behaviour such as poverty, unemployment and family responsibilities discussed above. Even in the most successful of studies using the Health Belief Model and the Health Locus of Control, investigators have shown differing results and much of the variance in health related behaviour cannot be accounted for.²⁸ For example, Calnan and Rutter used the Health Belief Model in a study of the relationship between health beliefs and health behaviour with respect to breast self-examination. They found that the relationship was more complex than the Model had led them to expect, and concluded that there were possibly confounding factors not included in the calculus.²⁰

Health beliefs and cancer

Investigations into health beliefs with respect to cancer draw on a number of influential studies of health beliefs in general.^{11,29-36} Although in effect, these studies focused on the 'white' ethnic majority, and were blind to considerations of ethnicity. (In some parts of the UK, it is important to remember that so-called ethnic minorities form the majority). Where the health beliefs of minority ethnic groups have been investigated, most work has focused on one ethnic group, in one particular geographical location.³⁷⁻⁴⁶ In these cases, investigators have sought out respondents from sizeable minority groups living in a particular area, for example, West Indian women in Hackney,⁴¹ Vietnamese in Greenwich.⁴⁰ In certain parts of the country, several sizeable minority ethnic groups may coexist allowing for comparison as happened, for example in Bristol, which permitted the health beliefs of five minority ethnic groups to be investigated.⁴⁷ Geographical proximity may provide a good reason for researching more than one ethnic group. Where it does not apply, it may be difficult to justify the study. For example, although anecdotally interesting, the design of one study which looked at the health beliefs of members of the Punjabi community in Southall and Moroccans in North Kensington, seems spurious; the only characteristic shared is migration.⁴⁸ In order to make meaningful comparisons a large number of respondents are required. This will however require considerable research monies. Very few researchers will be able to match the national study undertaken by the Health Education Authority.⁴⁹ This is a study on health-related behaviour, attitudes and information, and experience of health services of Indians, Pakistanis, Bangladeshis and African-Caribbeans. The data are quantitative, although a number of focus group discussions were held to guide the design of the questionnaire. It is a good example of how the two methodologies can complement each other. Unfortunately the qualitative data were not published. Smaller-scale studies can only be considered exploratory. For example, despite purposefully selecting equal numbers of respondents from seven ethnic groups - including white - in different parts of England, the investigators urged caution in making inter- and intra- community comparisons since numbers perforce were relatively small.⁵⁰

The Bristol study used a translated interview schedule developed previously for a national study which had been blind to ethnicity.³⁶ This allowed them to make comparisons between the white ethnic majority and the minority ethnic groups studied. As far as we have been able to ascertain, only two studies have included respondents from the 'white' ethnic majority together with minority ethnic groups at the design stage.^{51,52} The Health

Education Authority had intended running a parallel investigation of the general population.⁵⁰ However developmental work which preceded the survey suggested that some themes or questions used for the general population were either inappropriate or irrelevant for the minority ethnic groups targeted. They also concluded that questions on language and communication which are crucial for minority ethnic groups are irrelevant to the white majority, notwithstanding the platform and evidence of the Plain English Speaking Campaign. The parallel investigation was abandoned. Instead data for the general population are drawn from an earlier study.⁵³

The investigation of health beliefs of minority ethnic groups with respect to cancer has been neglected. Indeed a major criticism of health research regarding minority ethnic groups is its tendency to focus on conditions thought to be peculiar to them, for example mental health problems in African-Caribbean men, haemoglobinopathies and rickets in South Asians. By focusing on one condition and one minority ethnic group at a time, there is an ineluctable tendency to 'blame the victim', dismiss the significance of poverty and other sources of deprivation and ignore racism and other structural impediments to accessing appropriate health care.⁵⁴⁻⁵⁸

At the time of writing this paper, none of the investigations into health beliefs with respect to cancer has set out to consider the significance of ethnicity.^{23,59-65} Where ethnicity has arisen, it has been more by accident than by design.^{66,67} Ethnicity has however been considered in relation to its influence on preventive behaviour: for example, attendance for screening for cancer of the breast and cervix.^{15,52,68-75} Ethnicity may have been overlooked because the incidence of the cancers which predominate in the white ethnic majority is lower in minority ethnic groups. However the belief that the incidence of cancer is lower in minority ethnic groups is based on mortality data and not on the numbers of people living with the disease. Furthermore the rate is expected to increase as a result of demographic changes such as ageing, and increasing exposure to environmental risk factors.⁷⁶ Now that equal representation in research is increasingly being emphasised,⁷⁷ investigators may be under pressure to consider ethnicity in their work, which means they will have to include people from minority ethnic groups in their studies and pay more attention to cancers which are more common in those groups.

Ethnicity

Complex historical processes are responsible for the way in which data are collected and analysed. For example, since 1911, English data have been analysed with respect to the Registrar General's five broad occupational categories; only recently has ethnicity been considered in research, and in some instances, its inclusion has encountered considerable hostility in minority ethnic groups.⁷⁸ In contrast, in the US, data are reported with respect to ethnicity; the collection of data on class and income is considered controversial.^{79,80} Although almost every US study of health beliefs is analysed with respect to ethnicity, for reasons outlined in the introduction of this paper, we consider only British investigations.

A relationship between social class and health beliefs has been established in the 'white' majority ethnic group. However social class classifications may be misleading with respect to ethnic minorities. They were devised in Edwardian England and reflect social values and conditions that prevailed at the time. They exclude children, housewives, retired people and the unemployed - now some 40% of the population on average, but up to 50% in some places,⁸¹ and are insensitive to the social and material circumstances of people from minority ethnic groups. Working in a small business places people in social class two, but minority ethnic businesses are often marginal and their owners may be quite poor. Migration can dramatically change a person's economic circumstances. Furthermore, many migrants support families in their country of origin. Unemployment is known to be

higher amongst certain minority ethnic groups.⁸² Another difficulty is the unquantifiable numbers of people declaring themselves to be economically inactive but who may be working. Educational achievement is not a good predictor of employment status. Housing may be a better measure but patterns of ownership and occupation are bound by ethnicity.

Recently the use of the concepts 'race', 'ethnicity' and 'culture' have been heavily criticised by health researchers.^{58,83-85} The voices of epidemiologists have been the most insistent in these debates. It is crucial to recognise that what looks like a difficulty to an epidemiologist may in fact be crucial data to other investigators. A good example is 'race' which emerged as a biological category in the eighteenth century, and was used in evolutionary biology and anthropology to rank peoples below the level of species; in a typical classification, white, middle-class Englishmen were placed at the top with English women, the lower orders, and other 'races' ranked below them. In the late twentieth century, some investigators became reluctant to use the term 'race' because of its association with systems of political, economic and social subordination, most notoriously slavery of black Africans, the Nazi's programme of racial hygiene, and the system of apartheid in South Africa. Recently the validity of 'race' as an independent variable in epidemiology has been discredited by, amongst other things, evidence which shows that no group of people possesses a discrete package of genetic characteristics. Furthermore genetic diseases are not confined to specific 'racial' groups. Nevertheless in other contexts, the concept 'race' is emphasised in order to demonstrate how racism structures economic and social disadvantage and relationships of domination and subordination. Hence 'race', above all a political construct, may be highly relevant in considerations of unequal access to health care.⁸⁶⁻⁸⁸

Ethnicity refers to practices and outlooks that distinguish a given community of people.⁸⁹ What holds a community together - or creates internal divisions within it - are real, or probable, or in some cases mythical, common origins, values and conventions. Culture refers to the ways of life of the members of a society, or of groups within a society.⁹⁰ Ethnicity and culture seem interchangeable. Both are woolly categories. However ethnicity is the term in general use in the research community for two reasons. First, the tendency in the past to talk about 'culture' was heavily criticised on the grounds that it encouraged analysts to explain variations in health and disease and health service utilisation in terms of cultural pathology. Variations in health and disease, it was argued, could be evened out with appropriate education and cultural assimilation. Not only did this approach (mis)represent English culture as 'healthy', it ignored aspects of other cultures which were 'healthy'. The official 'Stop Rickets Campaign' for example, which sought ways of eradicating the disease in the 'Asian' communities, failed to acknowledge that the white British diet was sufficient in Vitamin D only because of fortification. Yet the DHSS refused to fortify chapati flour in the way that margarine and cereals had been fortified for the white community.⁹¹ Instead they focused on changing attitudes and behaviours. It was further argued that this focus on culture had discouraged recognition of the subtle and crucial effects of racism and racial discrimination on social factors such as employment, unemployment and housing conditions.⁹² The 'Stop Rickets Campaign' attributed the prevalence of the disease in Asian women to their culture's insistence that they are locked away; there was no mention of racist attacks which made many women reluctant to leave their homes.

Secondly, 'culture' brings to mind 'higher things' such as art, literature, music and painting whereas the elements generally considered as contributing to ethnicity are actually language, religion, work, diet, or family patterns.⁹³ It is almost impossible to operationalise ethnicity in epidemiology; populations do not admit the level of generality demanded by the discipline. Beliefs and behaviour cannot be assumed from ethnicity however defined. There are for example, substantial variations in lifestyle and socioeconomic characteristics in the British Jewish

community. Another problem is that many of the features used in definitions of ethnicity are common to different groups; it is not possible to predict with confidence what membership of a so-called ethnic group entails. Diet for example, an important consideration in epidemiological investigations into coronary heart disease, resists neat classifications. Bagels smeared with cream cheese and laden with smoked salmon have been described as 'among the triumphant inventions of the Jews'.⁹⁴ Yet in Hackney, bagels are now very popular amongst other ethnic groups; a majority of the bakeries which sell them do not observe the dietary rules of *kashrus*, mix meat and cheese, and hence are out of bounds to the large community of ultra-orthodox Jews who live there. If the rules of *kashrus* are not complied with, it is also likely that the bagels would not be eaten by observant Muslims, who, in Hackney, have either Bangladeshi or Turkish origins. Both may observe the dietary rules of *halal*, however their diets have nothing in common.

It has been shown that ethnic categories selected by investigators are sometimes meaningless. A good example here is the use of the term 'Asian' which in Britain is taken to refer to people who have origins in Pakistan, Bangladesh, India, Sri Lanka and East Africa, whereas in the US it refers to people from China, Japan, Korea and so on.⁹⁵ The term also confers ethnic homogeneity on people with little in common save some form of association with the Indian sub-continent. However, although the term 'Asian' is inappropriate and even offensive, people who have origins in Pakistan, Bangladesh, India, Sri Lanka and East Africa understand that it refers to them because it has been so widely used.

Until the early 1980s, it was the practice in research to base ethnicity on the interviewers' own assessment. This approach is highly unreliable and open to accusations of bias.⁹⁶ Furthermore the investigator's perception of a respondent's ethnicity has been found to be at odds with an individual's self-identification.^{86,87,95} It is now considered at best inappropriate, at worst offensive, not to ask people to identify their own ethnic origin. However the question may be considered impertinent, and even threatening as was shown by investigations into the acceptability of including an ethnic question in the 1991 Census. Some respondents, especially 'Asians', resented the suggestion that they might not be British if not born here. Others, especially black respondents, thought the information would be used against ethnic groups.⁹⁷ The researchers responsible for the Health Education Authority's survey found screening for ethnicity one of the most difficult and sensitive parts of the interviewers' work⁵³ because some of the terms they used were not understood or could cause offence. It would have been helpful if they had indicated the terms which should be avoided. At the time of writing this paper, consideration is already being given to the manner in which ethnicity should be included in the 2001 Census.

Many people, especially white people living in Britain, tend not to think of themselves as having an ethnic identity. However, according to the above definitions, everyone has 'ethnicity'. Hence the 'white' ethnic majority should always be included in investigations. In some situations, a white or black skin may provide people with a sense of shared destiny. However there is a real danger of once again imposing homogeneity on people with nothing in common save a skin colour: Christian scientists are lumped together with atheists; meat-eaters with vegans; Welsh Nationalists with stockbrokers living in the Home Counties.⁸⁵ Perhaps the time has come to develop categories that more appropriately describe the ethnicity of white people. Once white people recognise that they too are characterised by ethnicity, we may all accept ourselves as belonging to an ethnic group.

Clearly the number of different possible answers to a question on ethnicity is great. One way of limiting them is to list them on a card. The Labour Force Survey for example offers respondents the choice of white, West Indian or Guyanese, Indian, Pakistani, Bangladeshi, Chinese, African, Arab, mixed origin, and other. People who said they were of mixed or other origin are asked to

describe their ethnic group in more detail. The information they provide is used to allocate them into one of the main listed categories.⁸⁴ Although susceptible to the claim that this is categorisation by investigator, the virtue of this approach is that it simplifies the task of data analysis. However it also over-concretises ethnicity. A US study cited in Leech, found that people's self-chosen ethnic identity may vary in time and place.⁹⁸ The extent to which this is the case in Britain is yet to be tested.

The fluidity of ethnicity is inconvenient for investigators intent on systematic analyses. They are advised to attend to the appropriateness of their categories,⁹⁵ to be alive to the constantly developing and changing character of social relations and are warned against using terms which are unnecessarily offensive. Well-chosen categories can reveal patterns that may not immediately be obvious to respondents. Although difficult, engaging with the fluidity of ethnicity may enrich investigations into health beliefs; as Evans-Pritchard⁴ found, health beliefs occupy the same realm as other considerations that structure people's identities and everyday lives.

Recruitment of respondents

The tried and tested strategies used to recruit white English-speaking respondents may not work in investigations of minority ethnic groups for the following reasons. First, although the 1991 Census provides data on areas where significant numbers of ethnic minorities live,⁹⁹ it may prove difficult to track potential respondents down. Electoral and other registers such as FHSA lists are of limited use because people from minority ethnic groups may not appear on them; economic and political refugees and illegal immigrants in particular, may fear that they will be used to track them down. Furthermore, these registers are notoriously unreliable¹⁰⁰ because of high rates of mobility and homelessness, however defined, in some minority ethnic groups.¹⁰¹ Finally, it is difficult to determine ethnic origin by surname and forename of some people. To a limited extent, it is possible to determine who is of Asian and African origin.⁴⁹ However women who marry exogenously will be excluded. Names cannot be used to recruit African-Caribbean people.

Although ethnic monitoring of inpatients was introduced into the NHS in April 1995, it will provide only a limited source of potential respondents. Control groups may be established by screening neighbouring households.¹⁰² However, there are limitations to recruitment strategies dependent on hospital inpatients. They exclude 'healthy' people; respondents in investigations of health beliefs tend to be recruited from the non-patient population, that is, outside of the GP's surgery or hospitals. Furthermore, research suggests that people from minority ethnic groups receive an inequitable share of NHS services compared to the white population.¹⁰³⁻¹⁰⁵ It follows from this that inpatients may not be representative of their community.

Investigators who can command considerable resources will be able to follow the example of the Health Education Authority and use the national field force of a commercial market research agency to knock on doors to screen for ethnicity using addresses derived from Census data. Fieldworkers may have to be bilingual.⁵² Although knocking on doors may be effective,⁵⁰ it is inappropriate and insensitive to do so in the case of finding respondents who may be political or economic refugees or whose residential status is irregular. A low response rate should be anticipated in these instances. Another approach is that used by recruiters for market research organisations who stand in a public place such as outside a supermarket, and screen passers-by for suitability and willingness to participate. However different methods of recruitment are needed for communities scattered across the country, such as Vietnamese and Chinese people. Vietnamese refugees were deliberately settled in many different parts of the country and are gradually forming communities. Chinese people work mostly in the catering industry. They tend to establish businesses away from one another in order to avoid

competition. A team of imaginative investigators in Hull recruited Chinese respondents by randomly selecting Chinese 'take-away' shops from the Yellow Pages of the telephone directory.⁴³ Chip-shop workers were used as controls on the presumption - a mistaken one with respect to Hackney - that they would be white.

It may be possible to recruit respondents through GP surgeries, mother and baby and other health clinics, and health visitors. However, as with mosques, churches, synagogues, and other places of worship, respondents may not be typical.^{14,76} Some investigators have put up posters inviting people to participate in their research. Some people, especially elderly women, are illiterate in both English and their own spoken language, some of which have no written equivalent.

The tendency of researchers to use community leaders and community organisations to recruit respondents from minority ethnic groups is suggestive of the 'take me to your leader' strategy favoured by nineteenth century administrators of tribal people. There is no reason to expect people from minority ethnic groups to make greater use of community facilities than people from the white majority. Refugees for example may make considerable use of a community centre because it provides much-needed advice on how to obtain housing and other benefits. However people who have lived and worked in Britain for many years will have developed their own social networks and may not see a need for a 'community' facility. Again, in some instances, a personal introduction by a community worker/representative may be helpful in establishing contact with potential respondents.⁴⁶ However some community workers/representatives may overstate their influence. In the Bangladeshi community in Tower Hamlet, for example, the authority and reputation of community representatives is susceptible to shifting political and religious tensions in both the UK and Bangladesh.¹⁰⁶ Although they speak the same language, health advocates may be of a different ethnic background, or higher social status, than the people being sought as respondents. One method which, as far as we have been able to ascertain, has not been tried by researchers, is to use newspapers and radio stations which serve particular ethnic communities.

In kinship systems where paternalism is the norm, one person, usually male, may act as spokesperson for the family, and obstruct access to other relatives, especially if they are female. Investigators may have to convince the dominant male of the value of their work, something which, as far as we have been able to ascertain, no-one has as yet attempted. Where women are the respondents, and the interview or focus group is carried out outside of their home, then transport should be provided, and paid for, for women unused to travelling alone or on public transport, or fearful of racist attacks.

So far as we have been able to ascertain, nothing has been published on whether or not recruitment rates are higher where the recruiter shares the same ethnicity as respondents, and whether or not this applies to all ethnic groups. Whatever recruitment strategy is used, investigators may find that people from minority ethnic groups are reluctant to take part in research for the following reasons. Firstly the research question may be irrelevant to the pressing concerns of targeted research subjects.¹⁰⁷ Secondly, as recipients of racist, and substandard, health care, they may suspect the motives of the well-meaning researcher. Thirdly, some people may have directly experienced or be aware of unethical, even harmful, investigations in their country of origin.¹⁰⁸ Fourthly, in some studies, particularly those exploring topics of an embarrassing nature, it is considered advisable to ensure that group participants do not know one another. However, anonymity may not be possible in communities linked by kinship or drawn together through a fear of racism.¹⁰⁹ Finally assurances of confidentiality may not assuage the anxieties of political and economic refugees or people whose residential status is uncertain. These difficulties mean that investigators may have to forego random or representative samples and be satisfied with recruiting respondents opportunistically or through word of mouth (a snowball sample).

Communication

People who cannot speak and write English are largely excluded from medical research on the grounds that they are unable to give informed consent. As a result, researchers have almost no experience of working with some minority ethnic groups. One of the greatest challenges for investigators is communicating with respondents who do not speak English, or for whom English is a second language and perhaps is poorly understood. People's grasp of English may be adequate for everyday purposes, but insufficient for sophisticated social or psychological research.

A wide range of languages are spoken in Britain. For example, according to the London Borough of Hackney Translation and Interpreting Unit, 24 different languages are spoken in Hackney. Investigators have to select the most appropriate one, which may mean grouping together people inappropriately, for example Turks and Kurds, Cantonese-speaking Vietnamese and Chinese. This in itself may cause problems.

Language is not the only obstruction to communication: the success of an investigation may also depend on whether or not it is possible to match for age, gender and ethnicity, investigator and respondent. This is often easier said than done. The investigators of a study of elderly 'Asians' carried out in Leicester were unable to interview more than one in three of the Sikh respondents because experienced interviewers who spoke Punjabi were scarce and available only part-time.⁴⁷

Letters and questionnaires can be translated into different languages.¹¹⁰ The technique of 'back-translation' is used to ensure that the translation into the second language is accurate as well as being functional and conceptually correct.¹¹¹ If communication is through the post, it is important to recognise that the person whose name appears on the envelope may not be given the envelope, or may not be able to read its contents even if it has been translated into their own language.

Using interpreters and advocates as interviewers is fraught with difficulties. First, they may not be equally fluent in both languages; unbeknown to the investigator, they may fail to translate, mistranslate or edit the questions and replies.¹¹²

Second, just because someone can speak a language fluently, it does not follow that they are capable of translating and transcribing into written English respondents' replies with the degree of accuracy and sensitivity demanded by investigations

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into health beliefs. Third, the skills demanded of an interviewer are not the same as, and indeed may be inimical to, those sought in interpreters and advocates. Considerable training may be needed.¹⁴ Where investigations cover several language groups, it may be appropriate to use a commercial market research organisation which has experience of this type of work and employs experienced bilingual interviewers.^{15,52,105} It is important to bear in mind that the ethical codes which guide commercial market research agencies are not as demanding as those governing medical research.

Investigations into the health beliefs of the white majority have been rightly criticised because researchers do not commonly report on the actual process or means of analysis by which categories of beliefs/health concepts have emerged from raw data.¹⁰ It is therefore hard to estimate how much of a researcher's own interpretation or subjectivity has gone into the analytic process. Investigations into health beliefs demand close attention to language. Where respondents do not speak English, or have English as a second language, errors in translation of specific words may distort and invalidate findings. Hence investigators exploring the health beliefs of minority ethnic groups must report in detail on their assumptions and methods. They should list the questions/types of questions that have been used to elicit the raw data in the first place.

The Health Education Authority consulted a wide range of community organisations and individuals on which topics might prove sensitive and, where possible, avoided them.⁵⁰ Inevitably talking about cancer will raise fears and concerns in some respondents. But that is not a good reason for not mentioning it. Instead consideration should be given to providing respondents with appropriate information and advice. For example, in an investigation into health beliefs with respect to breast cancer, health advocates have been trained to answer questions, give advice and allay unwarranted anxieties in respondents at the end of each focus group meeting.¹⁶

Conclusion

Our overall message is that investigators should avoid stereotypes and generalisations. It is of paramount importance that any work addressing the above topics, makes explicit the lessons learned, whether they be good or bad, so that others working in the area may benefit from their experience.

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